

DARE TO DIALOGUE:

Engaging Parents in System Change

By Patrick Graham, Sara Kennedy, and Johanna Lynch

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Sara Kennedy, an occupational therapist by training, is director of the Colorado chapter of Hands & Voices, a nonprofit organization with 45 chapters in the United States that networks with professionals and offers support to parents of deaf and hard of hearing children. She is the editor of the quarterly newspaper, *The Hands & Voices Communicator*, and coauthor of the manual *Bridge to Preschool: Navigating a Successful Transition*. Kennedy is the mother of four children, including a high school-aged daughter who is deaf.

As professionals, we are satisfied when we know our clients and students derive benefit from our expertise, our concern, and often our love. Nevertheless, these benefits cannot begin to equal the power of determined parents whose love for their child causes them to be powerful advocates at all levels of our society. Parents can move mountains for their child ... and they often do. They are frequently instruments of change in programs—for the better (DesGeorges, Kennedy, & Opsahl, 2010).

When parents and professionals have high expectations for their students and work together to create opportunities for them, children are “more likely to achieve more, to have higher levels of self-esteem, and thrive” (Szarkowski & Fournier Eng, 2014). State teams that actively collaborate with parents gain new perspectives, ideas, and energy.

Our own statewide transition planning teams have welcomed the authors—three parents who are also professionals active in the deaf educational community—into their discussions and planning. These teams—part of pepnet 2, the federally funded project with the mission to increase the education, career, and lifetime choices available to individuals who are deaf or hard of hearing—are located in our home states of Oregon, Colorado, and North Carolina. When we meet with pepnet 2 team members, representatives from vocational rehabilitation offices, state education agencies, local education agencies, schools for the deaf, and deaf adults, we experience teams that are nearly ideal.

An ideal team is one in which parents collaborate freely with professionals with no question off limits; it has clear objectives, norms, standards of practice, and history available to all. These ideal teams include stakeholders mirroring our community’s wide continuum of language, cultural diversity, and experience. Representatives come from state education agencies; vocational rehabilitation; local districts; and public, charter, and schools for the deaf. Parents of current or recent students from a variety of backgrounds and geographical areas and the students themselves also participate, adding immeasurably to the 360° view of transition planning.

Photos courtesy of Patrick Graham, Sara Kennedy, and Johanna Lynch



Clockwise from top left:
Oregon team members (from left to right) Eleni Boston, Camille Atkinson, Patrick Graham, Miranda Featherstone, Becky Emmert, Katie Heise, and Kathy Eckert-Mason; Eastern North Carolina School for the Deaf students Darian Smith (left) and Elijah Jones considering postsecondary options; North Carolina team members share ideas.

For teams involving the education of deaf and hard of hearing students, communication—how we handle signing and speaking—remains a frequent discussion, not just a discussion that occurs at the beginning of a series of meetings. Everyone is involved as we discuss specifics. For teams, specifics include questions such as: *Where are the gaps? What alterations in professional preparation, parent and student training, or transition activity alignment with post-school goals do we need?* These are amazing discussions!

Barriers to Parental Engagement in Meaningful Collaboration

Parent participation is often a requirement for state teams to convene or receive funding, and, too often, parents find their names listed among the collaborators and feel that they are not expected to participate meaningfully or make a substantive contribution. More than a few professionals have indicated that they find it difficult to engage parents; they say that

engaged parents are rare exceptions. We submit that parents sometimes require understanding to engage in a meaningful way; advocates are nurtured, not born. Enabling parents to connect with each other can revolutionize the dynamics in a classroom or in a district. Connecting parents enables modeling and mentoring. Observing another parent solidly fill a stakeholder role empowers the new, unfamiliar parent.

While engaged parents can ensure a healthy team perspective, professionals and parents will want to be mindful of potential pitfalls. As in teams composed of only professionals, teams in which parents participate may experience personality clashes, cultural conflicts, or the dominance of unrelated individual agendas. Designating one team member as facilitator at the beginning of meetings can help keep the focus on the goals of the team at large. We have learned that checking in with each other for alignment and readjusting when necessary has led to success.

Johanna Lynch is a parent educator with BEGINNINGS for Parents of Children who are Deaf or Hard of Hearing in North Carolina, and she participates in state councils and committees to improve the lives of deaf children. A mother to two teenagers, Lynch became interested in learning about deaf education and helping other families when her son was identified with a hearing loss at 2 years old.

The authors welcome questions and comments about this article at grahamp@mail.wou.edu, Sara@cohandsandvoices.org, and jlynch@ncbegin.org, respectively.

Parents respond to invitations that are tailored and specific. Compare an invitation such as: “*We need you because of your experience with dual enrollment [or other specific topic] ...*” to an invitation that simply asks for “... help in filling the parent seat on a committee.” Tying participation to the parent’s interest and skills is critical. So is inviting parents early, often, and at different times. Once a parent agrees to participate, welcoming him or her as a co-investor in deaf education sets the stage for ongoing engagement and alleviates the concern that he or she won’t be treated as an equal member of the team.

More often we find parents feeling their input is extraneous, neither wanted nor needed by educators or their children in the midst of transition. By the time a teen enters the tumultuous transition years, many schools have effectively trained parents to simply drop off their children and pick them up later. Further, students themselves want less parental input at this age, stretching their wings to make their own choices. However, this is a time when children and schools still benefit from parental engagement, and children still need the practical support and occasional coaching that can only be provided by their parents.

Parents tend to travel to professional locations instead of a mutually agreed upon spot despite the fact that they face logistical challenges participating in task forces that conflict with work or caregiving hours. Some districts make this natural challenge even more difficult. For example, one of our districts begins its high school accountability meeting at 7 a.m. but does not allow students to come until 7:45 a.m. While this may make it easier for professionals, it adds to the coordination demands for many parents who are often already overburdened. These individuals bear financial burdens for missing work, and they must compensate for travel expenses and child care during times when others on the team are likely on “work time” and paid.

Even more problematic: Some

Making It Meaningful: Bringing Parents into Collaboration

- Find parents from referrals by professionals and parent groups. People get involved because of relationships.
- Reimburse parents for travel and child care if needed.
- Plan for team building when new members join collaboratives.
- Share system vocabulary and processes with new members.
- Orient new parents to available regulations, laws, and governing systems.
- Encourage parents to use their unique skill sets to their best advantage.
- Create a team culture that welcomes questions and flexibility.

professionals question whether a parent can focus on the needs of all children rather than on those of his or her own child. All of us have stories to tell, and someone who has not felt he or she has been heard might continue to tell the same story. Just listening can make a parent finally feel understood. Further, thoughtful orientation in which parents are educated about experiences that are urban or rural, college or vocational, visual or auditory can broaden their perspective.

Professionals also worry that parents may ask charged questions, questions that professionals hesitate to address. However, these questions, sometimes involving topics considered politically incorrect, need to be addressed. In fact, these questions can lead to impassioned discussions that inspire changes in outlook or even generate system change. It may be important when a parent asks: “Why *do* we do that?” or “Why *can’t* we do that?”

Getting members to meet regularly, on schedule, and setting up a structure to ensure progress is a challenge for any team. If parents are not part of the day-

to-day work or informal gatherings of other team members, they may feel isolated. Practically speaking, parents like any other member of the team, need sufficient lead time to respond to requests or to schedule a meeting. Perception that a parent is unable to attend because of consistently short notice or, even worse, left out of a meeting altogether because other team members see each other often and informally can squelch parental enthusiasm and perhaps even cause individuals to leave the team. Clear, frequent, and open communication is the first step to building a strong team.

In Colorado, what increased our momentum was the suggestion to work from our end goal backwards. We wanted to create a system that incorporated transition goals into student-led Individualized Education Programs (IEPs). We worked backwards from the goal, designing teacher training and parent supports for this aspect of the IEP. Working backwards from the goal helped us think in a different way about the obstacles we faced. Co-author Sara Kennedy

voluteered to take notes for our pepnet 2 meetings, just as her daughter was entering the transition, believing that the experience of notetaking would help her own understanding of transition processes. Four years later, she found that writing those notes not only helped solidify her knowledge but also made her aware of what she didn't know. Now she takes a much more active role in sharing what parents are experiencing around the state, assisting teams in developing transition resources such as curricula for teacher training and materials for parents.

Defining expectations takes the guesswork out of knowing whether an individual, particularly a parent, can commit to a long-term project. Our experience has taught us that consistency in membership is important; constant member attendance affords teams the opportunity to build on a shared experience and achieve success. Thus, team members should make a strong effort to maintain membership throughout the life of a project for the benefit of the team. They can only do this if they know, in advance, what their commitment must be.

In North Carolina, co-author Johanna Lynch found her team made significant gains once members were able to move past discussion of language and modalities. Her team took another leap forward after participating in pepnet 2's first annual Summit. The time afforded by pepnet 2 allowed Lynch and her team to retreat from daily responsibilities and address an agenda that centered on the transition of our students; it catapulted the group's momentum. Having dinner together every night taught team members more about each other, not just as team members but also as people. The respect team members held for each other grew exponentially. In addition, they learned they really enjoyed each other's company.

Give Parents the Tools

Parents need the same tools as other team members:

- a working knowledge of the team's vocabulary,
- a history of team members and the organization each member represents, and
- a knowledge of the historical challenges affecting each day's work.

With those tools, parents can jump in and help the team tackle the issues at hand.

Who is Missing?

No single parent should always represent family interests. Over-focusing on a single parent is an easy trap to fall into, especially if the parent is also a professional and can (conveniently) "wear two hats" in any situation. These individuals easily become the go-to parents. Teams may want to consider selecting parents who can represent the full spectrum of family needs and leave the professional persona and ties to a single agency out of the discussion.

Coauthor Patrick Graham's son is currently in the first grade, and Graham joined the pepnet 2 team knowing that preparing for school to higher education or workplace transition is critical throughout a child's life. When parents educate their children about different transition opportunities, the children can educate their peers and even more families benefit. During one of its state conferences, the Oregon team had a panel of students discussing their experiences with transition, and that learning was so rich that the team decided to repeat it this year.

As parents invited to participate as active and meaningful contributors, we need to continually assess whether we can represent the needs of all families, not just the families who have children like our own. This requires that we learn about the cultural and linguistic variety represented in our community. A commitment to filling our own gaps of knowledge through objective, open, and respectful participation or pulling in the experience of other parents is imperative to create an initiative that serves all

children.

Parents bring the day-to-day reality of raising a child to every meeting. They already know that transition must start sooner, activities need to be more experiential, job or volunteer experience is critical, and independence comes in steps rather than suddenly during senior year. Engaged parents know that teachers have very little preparation in the area of transition, and it doesn't take long to realize that school administrators often don't understand the unique needs of the small population of students who are deaf or hard of hearing. Thus, parents and likeminded professionals are slowly driving the shift to an expanded curriculum for our children that will include tools to navigate the move from high school to college and career.

As parents, we ask professionals that they give us a chance to grow among individuals who value the parent perspective. We appreciate pepnet 2's emphasis on finding ways for parents to build ongoing capacity in transition to improve outcomes for our youth. We look forward to that shift as more active parent leaders and dedicated professionals pursue the same goal: children who become adults that are fully capable of self-determination and success both in their personal lives and in their careers.

References

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